

## Patient information

# What is Sarcoidosis?

Sarcoidosis or sarcoid, is a disease due to a particular type of inflammation, called granulomatous inflammation. Sarcoidosis can affect any part of the body, but most commonly affects the lungs, skin and eyes. In most people sarcoidosis is an incidental finding when they have a chest x-ray.

The disease can develop suddenly and then disappear, or appear gradually and produce symptoms that come and go. In the latter case the disease can continue to recur over a lifetime.

Although sarcoidosis can occur at any age, it mainly affects people between 20 to 40 years of age.

## What causes sarcoidosis?

No one knows what causes sarcoidosis. What is known is that it occurs all over the world. It is difficult to know how many people are affected as sarcoidosis can often be mistaken for other diseases. Furthermore, many people without symptoms may not know they have the condition.

If you are diagnosed with the disease there are many things that you can be reassured about:

- Sarcoidosis often goes away by itself. In cases where the disease persists you can generally continue to have a normal life.
- Sarcoidosis is not contagious. Although it can occur in families, there is no research to show that it can be passed from parents to children.
- Sarcoidosis is not a form of cancer.

## How will sarcoidosis make me feel?

The symptoms of sarcoidosis depend on what part of the body is affected. Most people with sarcoidosis have no symptoms at all. The commonest presentation is:

- A painful red, bumpy rash on the face, arms or shins called erythema nodosum.
- An illness with flu-like symptoms of fever, tiredness and joint pains.
- Shortness of breath: known as dyspnoea, a persistent dry cough and a chest discomfort. A chest x-ray may show swollen lymph glands in the chest
- Sore eyes and blurred vision due to inflammation within the eye, known as uveitis.
- Swollen glands in the neck, armpits and groin.
- Other symptoms: high calcium level in the blood and urine, painful joints, problems with nerves causing weakness and abnormal sensation.

## How is sarcoidosis diagnosed?

It can sometimes be difficult to diagnose sarcoidosis, as it can mimic a number of other conditions. Therefore, tests will need to be carried out.

- **A chest X-ray** will show the areas of the lung that are affected by sarcoidosis and any swollen lymph nodes.
- **A CT scan** may be performed to look at the lungs and lymph nodes. In some cases a CT scan is diagnostic of sarcoidosis and further tests in particular biopsy may not be necessary.
- **A bronchoscopy** may be undertaken. It is a procedure to inspect the inside of your lungs using a very fine flexible tube. If necessary some samples will be taken.
- **Lymph node biopsy** is occasionally taken, which is a procedure performed under anaesthetic to get a sample of the swollen gland, which can then be seen under a microscope to confirm the diagnosis.

- **A specific blood test** can measure a blood substance called angiotensin-converting enzyme (ACE). This blood test can sometimes be useful to follow the activity of the disease.

## **What is the course of the disease?**

Sarcoidosis may often be active for a period of months to years and then improve without treatment and cause no further problems. Because of this it is common for doctors to observe a patient's symptoms and tests for a period of some months before considering treatment.

A milder form of illness can last from some months up to two years, before the sarcoidosis is completely resolved.

In some patients where symptoms are severe or an organ is seriously affected treatment will be started straight away therefore these patients will need to be followed up for many years by specialists in the hospital.

## **How is sarcoidosis monitored?**

Your doctor will wish to see you on a regular basis to monitor the disease. Your condition will be monitored through:

- Chest X-rays
- Breathing or lung function tests
- Blood tests including the serum ACE

The results of these tests will help the doctors to decide how best to manage the treatment of your particular symptoms.

## **What treatment will I be given?**

Not all patients with sarcoidosis need drug treatment. Treatment is necessary for patients who have the rarer forms of sarcoidosis that affect lung tissue and cause lung symptoms (to prevent lung fibrosis), or affect brain, heart or if it causes a high blood calcium level.

If you develop lung problems your consultant will monitor you through outpatient appointments for a few months to see if you get better on your own. If the lung

involvement is severe, causing you problems or getting worse, you will be offered treatment.

The main treatment for sarcoidosis is steroids. Sarcoidosis responds very well to steroids. These are usually started at a moderate dose and then reduced gradually over a few months with the aim of stopping treatment after about one or two years. If patients require a high dose of steroids to control their sarcoidosis, other medication may be used in an attempt to reduce the amount of steroids needed (azathioprine, methotrexate and hydroxychloroquine).

Occasionally the sarcoidosis may become active again after steroids are stopped. This is called a relapse. Symptoms will respond to restarting of the steroid treatment. Steroids may have significant side effects including blood pressure, diabetes, osteoporosis, weight gain, bruising, and your doctor will discuss the benefits and risks of steroids with you.

### **Three Important things:**

- **Sarcoidosis is** often not a serious disease and in some cases will resolve with or without treatment
- **It is not infectious or a cancer**
- **Less than a third of people with sarcoidosis will require steroid treatment**

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